Advance Care Planning and The Conversation Project

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Objectives

• Understand current state of advance care planning in the United States
• Discuss impact of advance care planning on medical care delivery to patients
• Review developments in advance care planning, including The Conversation Project

Autonomy

• American society strongly values autonomy
• Past 50 years deference to patient autonomy has gradually replaced paternalism
• Prompted by legal cases where families contested life-sustaining care that physicians imposed upon patients
• Culminated in Patient Self Determination Act 1991, which protects right of patients to accept or refuse treatments, make their own medical decisions


Advance Care Planning

• Advance care planning helps to honor patient autonomy around end of life care
• Honors patient preferences and goals if incapacitating illness or injury prevents adequate communication
• ACP designates patient choices about medical care for when a patient is unable to indicate their preference
• Choices depends upon patient’s care goals
• Some prioritize longer life
• Some choose not to prolong life if QOL unacceptable
• Affected by religious and spiritual values and beliefs

Advance Care Planning Facts

90% of people say that talking with their loved ones about end-of-life care is important.


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Only 27% have actually done so.

60% of people say that making sure their family is not burdened by tough decisions is "extremely important."

Source: Centers for Disease Control (2005)

But 56% have not communicated their end-of-life wishes.

Source: Centers for Disease Control (2005)

80% of people say that if seriously ill, they would want to talk to their doctor about end-of-life care.

Source: Survey of Californians by the California HealthCare Foundation (2012)

Only 7% report having had an end-of-life conversation with their doctor.

Source: Survey of Californians by the California HealthCare Foundation (2012)

82% of people say it’s important to put their wishes in writing.

Source: Survey of Californians by the California HealthCare Foundation (2012)

23% have actually done it.

Source: Survey of Californians by the California HealthCare Foundation (2012)
**Advance Care Planning Facts**

70% of people say they prefer to die at home.

76% die in an institution (hospital, nursing home or long-term care facility), and receive more aggressive, invasive, poorer quality care than they would at home.


**Advance Care Planning**

**Drastic need for expansion and improvement of ACP in US**

- 2003 Agency for Healthcare Research and Quality (AHRQ) report: fewer than 50% of severely or terminally ill patients had an advance directive in their medical records
- Advance directives helped make end-of-life decisions in less than half of the cases where advance directives existed


- The care that people receive at end of life does not often fulfill their wishes, and is often more aggressive and invasive than desired.

The SUPPORT Investigators. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). JAMA 1995;274:1592-1598

"It is thorazine in appearance but I need to order a battery of tests."

**Chronic Illness in America**

7 of 10 Americans die from chronic disease.

9 of 10 deaths in Medicare population are associated with these chronic illnesses:
- Congestive heart failure
- Chronic lung disease
- Cancer
- Coronary artery disease
- Renal failure
- Peripheral vascular disease
- Diabetes
- Chronic liver disease
- Dementia

Dartmouth Atlas of Health Care www.dartmouthatlas.org

- Health declines slowly
- Marked by sudden severe episodes of illness requiring hospitalization
- Pattern repeated over and over with overall health steadily declining
- Considerable uncertainty about when death is likely to occur
- Patients often not told condition is terminal
- No clear threshold between acutely ill and actually dying
- Patients often too ill to speak for themselves - physicians and family/surrogate make decisions
Chronic Illness in America

• 32% of total Medicare spending is for patients with chronic illness in their last two years of life (physician and hospital fees associated with repeated hospitalizations)

• Patients don’t get the kind of care they would want – they prefer a more conservative pattern of end of life care than they receive

• Patients with severe chronic illness who receive more intensive inpatient care do not have improved survival, better quality of life, or better access to care

• Patients’ experience of care differs dramatically; regions with much more aggressive medical patterns see medical specialists more frequently, spend more days in the hospital, die in an ICU more often

Robert Wood Johnson Foundation

International Comparison of Spending on Health, 1980–2009

Average spending on health per capita ($US PPP*)

Total expenditures on health as percent of GDP

Cost: Hospital Spending per Discharge, 2009
Adjusted for Cost of Living

What is this money buying us?

Among OECD member nations, the United States has the:

Lowest life expectancy at birth.
Highest mortality preventable by health care.

Organization for Economic Development and Cooperation

Medical Spending in the U.S.
$2.9 trillion in 2010

The costliest 5% account for 50% of all healthcare spending

CBO May 2009 High-Cost Medicare Beneficiaries www.cbo.gov
nhc.org/facts/cost.shtml

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Institute of Medicine Report on Dying In America

IOM report released September 2014
- Comprehensive report on current state of medical care for persons with serious illness or medical condition approaching death
- Consensus study assessed:
  - Delivery of medical care, social, and other supports to both person and family
  - Person-family-provider communication of values, preferences, and beliefs
  - Advance care planning
  - Health care costs, financing, and reimbursement
  - Education of health professionals, patients, families, employers, and the public at large
  - Focused extensively on people with serious and chronic illness of indeterminate prognoses
- Why the current health care system has largely failed to meet their needs, including advance care planning

Findings, Clinician-Patient Communication:
- Most people nearing the end of life are not physically, mentally, or cognitively able to make their own decisions about care.
- Of people who indicate their EOL care preferences, most choose care focused on alleviating pain and suffering.
- Frequent clinician-patient conversations about EOL care values, goals, and preferences are necessary to avoid unwanted treatment.
- Incentives, quality standards, and system support are needed to promote improved communication skills and more frequent conversations.

Recommendation:
Professional societies and other organizations that establish quality standards should develop standards for clinician-patient communication and advance care planning that are measurable, actionable, and evidence based. These standards should change as needed to reflect the evolving population and health system needs and be consistent with emerging evidence, methods, and technologies.

Payers and health care delivery organizations should adopt these standards and their supporting processes, and integrate them into assessments, care plans, and the reporting of health care quality.

Joint Commission

Recent Joint Commission Audit SCHS - deficiency on handling of advance directives at SCMC Bend
- Long standing Joint Commission requirement to ask if a patient has an advance directive on admission
- Joint Commission shared expectation that the health care team not only asks about existence of advance directive on admission but also:
  - If no advance directive to offer services to assist patient in completion of one
  - If one exists but not available to follow up with patient and family to locate the advance directive
  - Clear documentation of review of existing advance directive and its impact on medical decisions while a patient is hospitalized

What impact does ACP have?

Providing ACP assistance to patients with advanced illnesses
- Positively impacts quality of life
- Improves patient and family satisfaction
- Reduces surviving family anxiety and depression


- Associated with reduction in healthcare costs in patients dying with advanced cancer
What impact does ACP have?

ACP increases overall satisfaction with the health care process.


Patients with advanced illnesses, including metastatic cancer, may receive more aggressive treatment than they want because they have not discussed their end-of-life care preferences with their doctor.


What impact does ACP have?

Patients who received advance care planning or palliative care interventions consistently showed a pattern toward decreased ICU admissions and reduced ICU length of stay, and likely health care cost savings.


A comprehensive ACP program with high completion of advance directive suggests reduced health care costs in last 2 years of life as compared to national average.


What impact does ACP have?

Angelo Volandes, MD and team at Harvard developed videos to show patients and families visually what invasive medical care looks like ie. ICU, CPR, intubation and mechanical ventilation - "ACP Decisions"

150 hospitalized patients with prognosis 1 year or less randomized to verbal narrative vs. 3 min video describing CPR and intubation.

Patients who viewed videos were more than twice as likely to request DNR, DNI status at time of discussion and at discharge than control subjects.


"ACP Decisions” video outcomes:

150 patients at 4 cancer centers in Boston with advanced cancer randomized to verbal narrative vs. CPR video.

Participants with advanced cancer who viewed video of CPR were less likely to opt for CPR than those who listened to a verbal narrative (request for resuscitation decreased from 48% to only 20% with video)


Decision Aids for Advance Care Planning: An Overview of the State of the Science

Continuum of health states during which advance care planning may be considered.

Support 3 key components of the process:

• Learning about anticipated conditions and options for care
• Considering these options
• Communicating preferences for future care, either orally or in writing

Decision aid benefit depends on the patient's current health status and the predictability of illness trajectories:

• Healthy persons benefit most from general decision aids focused on choice of health care proxies, goals of care for hypothetical catastrophic situations
• For patients with serious illness, appropriate aids focus on decisions to accept, withhold, or terminate specific treatments
Decision aids improve advance care planning by facilitating clear documentation and by offering insights into why patients make the choices they do.

- Only 12% of patients with an advance directive had received input from their physician in its development.
- Physicians were accurate only about 65% of the time when predicting patient preferences.

Examples:
- **My Directives** – online platform for advance directives
  [Mydirectives.com](http://Mydirectives.com)
- **Five Wishes** – document specifies care preferences, meets legal requirements as advance directive in most states
  [Agingwithdignity.org/five-wishes.php](http://Agingwithdignity.org/five-wishes.php)
- **Consumer’s Toolkit for Health Care Advance Planning** – American Bar Association toolkit
  [Americanbar.org](http://Americanbar.org)
- **Caring Conversations** – Center for Practical Bioethics toolkit
  [Practicalbioethics.org/resources/caring-conversations](http://Practicalbioethics.org/resources/caring-conversations)
- **The Conversation Project** – Starter Kit and How to talk to your doctor kit
  [Theconversationproject.org](http://Theconversationproject.org)

**ACP Decision Aids for Patients with Serious Illness**

Move from hypothetical to actual clinical decisions as patient and family familiarity with health states increases.

Should be staged approach:
- Healthy persons encouraged to choose and document medical POA, complete general AD
- Patients with advanced illness provided specific information on condition, options for life-sustaining treatments, encouraged to name medical POA
  - Disease–specific tools

**ACP Decision Aids for Pts with Serious Illness**

Information needed for advance care planning for patients with advanced illness:
- **Prognosis**
  - More difficult for diseases with less certain prognosis ie. heart disease, dementia
- **Implications of health care decisions**
- **Expected natural history of their condition**
- **Efficacy or lack thereof or harm of various life-sustaining interventions**
- **Ongoing process rather than one-time decision, revised as the patient’s familiarity with their illness increases or disease progresses**

Examples:
- **Oregon Health Decisions Workbook**
- **PEACE (Patient Education and Caring: End-of-life) Series** from American College of Physicians
- **Healthwise:**
  - Should I have Artificial Hydration and Nutrition?
  - Should I stop kidney dialysis?
  - Should I receive CPR and Life Support?
  - Should I stop Treatment that Prolongs my life?

**POLST**

OR was the first state to enact POLST

POLST = “Physician Orders for Life-Sustaining Treatment”
- **Resuscitation (attempt or do not attempt resuscitation)**
- **Aggressiveness of medical interventions (full treatment, limited interventions, comfort measures only)**
- **Artificially administered nutrition (long term, defined trial, or no artificial nutrition by tube)**

16 states (OR, CA, WA, ID, MT, HA, UT, CO, IA, LA, NY, PA, WV, NC, TN, GA) have endorsed POLST or variation laws

30 other states have programs under development
### POLST vs. Advance Directive

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<thead>
<tr>
<th>POLST</th>
<th>Advance Directive</th>
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<tbody>
<tr>
<td>• Indicates patient wishes for aggressiveness of care at present time</td>
<td>• Indicates wishes for aggressiveness of care in potential future situations (close to death, permanently unconscious, advanced progressive illness, extraordinary suffering)</td>
</tr>
<tr>
<td>• Intended for patients with serious illness or medical frailty</td>
<td>• Intended for everyone</td>
</tr>
<tr>
<td>• Medical orders signed by provider</td>
<td>• Legally recognized document (cannot be interpreted or honored by emergency providers)</td>
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### Respecting Choices ACP Model

#### Three tier ACP based on patient state of health
- First Steps ACP
- Next Steps ACP
- Last Steps ACP

#### First Steps ACP
- Routine healthcare for all patients over the age of 55-65
- Wishes for life-sustaining treatment if the person suffers a severe, neurologic injury or illness and unlikely to recover
- Initiated at routine annual physical examinations by PCPs

#### Last Steps ACP
- Prognosis of 12 months or less
- Patients who live in long-term care facilities, at high risk for complications, at risk of losing their decision-making capacity
- CPR, artificial life-support, artificially administered nutrition and hydration, comfort care options discussed
- POLST completed to document wishes

#### Next Steps ACP
- Patients with chronic, progressive illness, functional decline, medical comorbidities, recurrent hospitalizations
- Risk for illness that might leave them unable to express their own wishes about their healthcare decisions
- Understand trajectory of illness, possible complications, life-sustaining treatments that may be offered if illness progresses
- Patient’s health care decision maker and family are involved
- Component of chronic disease management
Respecting Choices – Gunderson Lutheran
- Instituted in the early 1990's in LaCrosse, Wisconsin
- 540 Gunderson Healthcare system decedents study
- Very high prevalence of advance directives (85%)
- 95% of advance directives documented in the medical record
- Almost all advance directives requested to forgo aggressive life-sustaining treatments as death neared
- 98% of the patient deaths involved forgoing aggressive treatments and transition to comfort measures


The Conversation Project
- Co-founded by Pulitzer Prize-winner Ellen Goodman and developed in collaboration with Institute for Healthcare Improvement
- Public engagement campaign with the transformative goal to have every person's end-of-life wishes expressed and respected
- Dedicated to helping people talk about their wishes for end-of-life care
- The Conversation should be had at the kitchen table, not in ICU

The Conversation Ready Project - Pioneer Sponsors
- St. Charles Health System - only West coast Pioneer Sponsor with hospitals holding a rural designation
- Ultimate objective is to package proven methods and strategies to other health care systems internationally
  - Reach out to patients about their end-of-life wishes
  - Record end-of-life wishes in accessible fashion (EMR)
  - Respect patient wishes for end-of-life care

St. Charles TCP Pilot
- Established PCP Dr. Murphy - St. Charles Family Care Redmond
- Every patient 60 years or older seen in clinic for any reason over a 4 week period was presented The Conversation Project with advance directive materials
- Phone call follow ups from nurse ACP facilitator
- Goal: Provide advance care planning materials and start the conversation with 100% of patients age 60 or over seen in 4 week period
Results: 73 total patients
Age Range:  
50% 60-70yo  
28% 70-80yo  
18% 80-90yo  
4% 90-100yo
Reason for Visit:  
42% Follow up medical issues  
28% New medical issue  
9% Annual physical exam  
5% Hospital follow up  
2.5% Pre-op assessment  
2.5% ED visit follow up
Advance Care Planning materials provided to patients - 90%
Conversation documented in EHR by Dr. Murphy - 90%

Conclusions

The current state of advance care planning in the United States is dismal. This is now recognized, and great efforts are being made nationally to improve it. Encouraging advance care planning honors patient and family autonomy which is highly valued in American society. Advance care planning has the opportunity to help patients avoid potentially non-beneficial invasive treatments and procedures that they do not want to receive (that are costly), and therefore positively impact the financial outlook of the American health care system.

• All 73 patients sent a survey in the mail with specific questions regarding their actions since visit with Dr. Murphy - 35% response rate (26/73)
• 4/26 - already had an advance directive, reviewed it with their health care surrogate, all 4 stated copy of the AD in PCP’s EHR
• 5/26 - newly completed advance directive and discussed it with family and designated health care surrogate, all 5 found the conversation with Dr. Murphy very helpful and would provide Dr. Murphy with a copy of the new AD
• 9/26 - had the conversation with their family, did not complete the AD, found the conversation with Dr. Murphy somewhat helpful

http://theconversationproject.org/